

# Whose Job Is It?

## *Parents' Concerns About the Needs of Their Children with Language Problems*

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This study examined the perspectives of parents of children with specific speech and language difficulties in the United Kingdom and described the issues they raised when considering provision to meet their children's needs. The study used a mixed-methods approach. Data from interviews were analyzed using a computer-based qualitative interview analysis method (ATLAS/ti; Muhr, 1997), with reference to evidence from a parent-completed rating scale and assessments of the children's language and educational development. The issues generated by the analyses were considered in relation to whether the child attended mainstream or special school. Results are discussed in the context of current educational policies for inclusive education and parental participation in meeting children's educational and social needs.

Language is a cornerstone of early development. When a child's early language skills are compromised because of developmental difficulties, parenting patterns and educational provision are challenged. How parents and professionals work together to support the development of children with language difficulties is of significant concern. The current study addressed these issues by considering the perspectives of the parents of children with specific speech and language difficulties (SSLD). These are children with a primary language problem, one that is not a result of other intellectual, sensory, or physical difficulties; these children are often referred to as experiencing *specific language impairment* (Bishop, 1997; Leonard, 1998).

The involvement of parents in the education of children with disabilities in the United Kingdom is considered not only a right but also a necessary component of the delivery of effective and efficient provision (Department for Education and Employment, 1997, 1998). It is also a legal requirement under the Education Act of 1996 (Department for Education, 1996) and legislation that is comparable to that in the United States, the most recent being the 1997 amendments to the Individuals with Disabilities Education Act (IDEA 1997). Guidance is provided by a Code of Practice (Department for Education and Skills, 2001).

Parental involvement covers many aspects of education, including the assessment process, where parents' knowledge of their child is an important source of information; decision-making, where parents have a right to receive full information, call their own experts, and express a preference for provision;

and educational intervention, to which parents may contribute. Parents also provide an important source of information on the working of the systems designed to meet their child's needs. Although such information concerns an individual child's pattern of experiences, patterns across individuals can be analyzed and the results generalized to wider groups. As such, parents have an important role in closing the audit loop on the system's effectiveness.

As provision for children with disabilities is being made increasingly in inclusive settings in both the United States and the United Kingdom, it is important to understand parents' perspectives on the benefits and drawbacks of this approach. Parents of children with disabilities and parents of typically developing children have mainly positive attitudes about the inclusion of children with disabilities in mainstream classrooms (Bennett, DeLuca, & Bruns, 1997; Duhaney & Salend, 2000; Galant & Hanline, 1993; Guralnick, 1994; Guralnick, Connor, & Hammond, 1995; Miller et al., 1992). Parents who are supportive of inclusive policies consider that this means for their children acceptance, belonging, not being different, making friends locally, and participating in community activities (Erwin & Soodak, 1995; Hewson & Sisson, 1996; Petley, 1994; Schwartz, Staub, Galluci, & Peck, 1995). Parents who support inclusion consider that children with disabilities develop better social skills, academic abilities, and motivation from being placed alongside their typically developing peers, who act as role models (Guralnick et al., 1995; Palmer, Fuller, Arora, & Nelson, 2001; Ryndak, Downing, Lilly, & Morrison, 1995). Many parents assign greater importance to their

child being accepted socially and as part of the community than to his or her academic achievement (Bennett, Niswander, & DeLuca, 1996; Palmer et al., 2001).

Studies in both the United States and the United Kingdom that have explored aspects of inclusion, including parental views of supports needed and barriers encountered, have revealed variations in parental perspectives. Parents may lack knowledge of the services available (Wesley, Buysse, & Tyn-dall, 1997), although intervention programs at the community level may redress these deficiencies (Buysse, Wesley, & Skinner, 1999). Parents of typically developing children in inclusive schools have been found to hold more positive views about inclusion than have parents of children in noninclusive schools, and to believe that it was valuable to their child's development (Diamond & LeFurgy, 1994; Guralnick et al., 1995; Miller et al., 1992).

Parents may have concerns about the quality of the special support available and the possibility that the child will be rejected by his or her peers (Galant & Hanline, 1993; Guralnick, 1994; Guralnick et al., 1995). They may have to fight for the provision necessary, a task for which not all parents have the necessary resources (Petley, 1994). Riddell, Brown, and Duffield (1994) found that middle-class parents, either alone or in liaison with voluntary agencies, were more successful at gaining extra resources for their children than were working-class parents.

Concerns about inclusion also involve its suitability relative to the severity of the child's disability, the child's age, and whether the education of typically developing children will be affected (Palmer et al., 2001; York & Tundidor, 1995). Children with behavior problems seem to be rejected more often, and their parents are aware of the drawbacks of inclusion for them (Guralnick, 1994). Because children with SSLD frequently experience additional problems with behavior, there may be similar drawbacks for this population (Botting & Conti-Ramsden, 2000; Lindsay & Dockrell, 2000).

The age factor is relevant to both the language and the educational needs of children with SSLD. Speech and language therapists (SLTs) in the United Kingdom typically concentrate on the preschool and primary (elementary) age range (Lindsay, Dockrell, Mackie, & Letchford, 2002). The nature of the primary curriculum and classroom practice facilitates the delivery of in-class support, either by the SLT or by the teacher under the SLT's guidance. Speech and language therapists in the United Kingdom are developing in-school practice that facilitates program delivery within inclusive settings. As curriculum demands change in later primary school, it becomes more difficult to integrate therapy with teaching (Law et al., 2002).

Parents recognize that the philosophy of the school and the attitudes of individual teachers involved are important for successful inclusion (Bennett et al., 1997; Bennett et al., 1996; Erwin & Soodak, 1995; York & Tundidor, 1995). However, parents and teachers do not necessarily agree on the benefits of

inclusion (Bailey & Winton, 1987; Wesley et al., 1997). Seery, Davis, and Johnson (2000) reported that despite the apparent similarity of views between parents and professionals, a finer grained analysis revealed important divergences. For example, twice as many professionals as parents provided only a conditional affirmative response to inclusion. In addition, not all parents want inclusion for their child (Grider, 1995). In England, there were more parental appeals to the Special Educational Needs Tribunal against local education authorities that refused to grant a "special" rather than "mainstream" school placement than appeals by parents against refusal to grant a "mainstream" placement (Special Educational Needs Tribunal, 2000).

Many parents of children with special educational needs recognize that not all parents want the same type of education for their children. They would like to be presented with facts by supportive professionals and to be able to make a choice about education based on that information (Erwin & Soodak, 1995; Hewson & Sisson, 1996; Stokes, 1993). The complexity of the perspectives of parents of children with and without disabilities is evident from a review of 17 studies by Duhaney and Salend (2000). Parents who place a higher priority on socialization tend to favor an inclusive educational setting, whereas parents who are more concerned with academic goals tend to favor the availability of a continuum of services (Palmer, Borthwick-Duffy, & Widaman, 1998). Parents influence their children's development both directly through their own parenting behavior and indirectly through the decisions they make about their child, including those concerning schooling. Consequently, enhancing effective parental involvement, in both modes, is one means of optimizing the development of children with disabilities.

Bronfenbrenner's ecological systems theory (1979, 1992) provides a useful model for conceptualizing the factors relevant to helping children with developmental difficulties as well as their parents and schools (Granlund & Roll-Pettersson, 2001). It stresses the interconnectedness and hierarchical arrangement of four systems: micro-, meso-, exo- and macro-systems. There is no single focus on child deficiencies or the environment as explanations of poor development. The model is transactional and complex in that the child and the systems affect each other. The dimension of time in the changing pattern of interactions and nature of children's development has also been recognized (Lindsay, 1995). A concept of particular relevance here is that of "environmental niches," which are "particular regions in the environment that are especially favourable or unfavourable to the development of individuals with particular personal characteristics" (Bronfenbrenner, 1992, p. 194). This has relevance both to consideration of inclusion and to the particular aspect of parental involvement. Parents' perspectives, support, and understanding can enhance the match between the child's characteristics and the environmental niche. Their perspectives may include the perceived benefits and disadvantages of different types of education and therapy provision; parents may also act as practical interfaces

between other professionals and the child with respect to identification, assessment, and intervention (Roffey, 1999; Wolfendale & Bastiani, 2000). As consumers, parents also have perspectives of the operation of education and health-care systems and of their interaction. Finally, the values, laws, customs, and resources of a particular culture provide the context for parental perspectives on issues such as the philosophy and nature of inclusive education and on the laws and mechanisms, including financial priorities, that support it.

Public schools in the United Kingdom operate within local education authorities (LEAs), which are responsible for assessing children with severe and complex special educational needs (SEN) and providing the resources to meet those needs. Similarly, health care, including speech and language therapy, is provided by health trusts. Children considered to have special educational needs will be entered on the school's SEN register and have an Individualized Education Plan (IEP) devised by the teacher. When a child has more substantial and persistent SEN, professionals from outside the school, including SLTs and educational psychologists, will contribute to the IEP. When a child is considered to have severe and complex SEN, a statutory multiprofessional assessment is conducted, to which the parents must be invited to contribute, and the child may be made the subject of a statement of special educational needs. The statement specifies what provisions must, by law, be made to meet the child's special educational needs and lays the foundation for the development of further IEPs (Huefner, 2000). This status is applied to about 3% of school pupils, more than half of whom attend mainstream schools. There are now very few residential schools for children with SEN; these are mainly for children with low-incidence disabilities and are often run by voluntary bodies.

This study adds to previous work by focusing on children with SSLD and, in particular, on their parents' perspectives. The research combines qualitative and quantitative methods, using each to cross-validate the other. The special educational needs system in the United Kingdom does not require diagnostic categories; SSLD and SLI are both commonly used by practitioners to refer to children with primary language problems (Lindsay, Dockrell, et al., 2002). Although their nonverbal intellectual ability is normal and they have no major sensory impairment, these children have substantial language impairment, typically in both expressive and receptive language domains. This group of children is particularly interesting because, by the nature of their problem, they bring together professionals from health (speech and language therapy) and education. Also, their communication difficulties are typically not identified until they are 2 years of age or older. However, there is evidence of a mismatch in the understanding of these children's problems and their requisite needs as indicated by speech and language therapists and educational psychologists (Dockrell, George, Lindsay, & Roux, 1997) and gaps in teachers' knowledge and expertise to meet the children's needs (Dockrell & Lindsay, 2001). This study provides

evidence on parental perspectives regarding the effectiveness of inclusive education. This is explored as a wider system issue, beyond the school alone, to include education and health services provision. It goes beyond the examination of each to address the integration of services.

## Method

The present study was part of a longitudinal study conducted in two LEAs and two regional special schools for children with severe speech and language difficulties in the United Kingdom. One LEA is a large urban community in the north of England with one health trust and a population of 531,000; the other spans two health trusts, covers both rural areas and a series of small towns, and has a population of 599,000. This project focused on a group of 69 children with SSLD selected when they were in Year 3 (about 8 years of age). An initial survey of all educational (school) psychologists, speech and language therapists, and schools' special educational needs coordinators in the two LEAs identified 133 children with SSLD, from whom a subsample of about 30 from each LEA was derived. The 59 selected children were supplemented by 10 children with SSLD attending regional special schools. There were 52 boys and 17 girls, a gender disparity typical of samples of children with SSLD (Leonard, 1998). All children were on their school's special educational needs register, and 54% had a statement of special educational needs under the Education Act of 1996. The children showed substantially delayed development on a number of language and educational measures. Mean test ages ranged from 4 years 4 months to 6 years 1 month at mean chronological age of 8 years 3 months (Dockrell & Lindsay, 1998). The longitudinal study, using a mixed-methods design, examined the nature of the difficulties, including language and literacy, experienced by these children and the services provided to meet their needs. The present study of parental perspectives complements an investigation into the perspectives of the children's teachers (Dockrell & Lindsay, 2001).

Qualitative methods have become established within educational and psychological research (Denzin & Lincoln, 2000; Miles & Huberman, 1994) and, more recently, within special education (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999; Grove & Fisher, 1999; Palmer et al., 2001; Seery et al., 2000; Wesley et al., 1997). The use of individual and group interviews and focus groups allows a more flexible approach to data gathering and provides the potential for richer information, which may extend the scope of the study beyond the original research questions (Anzul, Evans, King, & Tellier-Robinson, 2001; Pugach, 2001). Qualitative methods also represent a different epistemological approach, treating the participant as a partner, providing an interchange of views between two or more people, and emphasizing the research as socially situated (Lewis & Lindsay, 2001). However, the quality of research using

qualitative methods has been criticized, including analyses sponsored by government agencies in the United Kingdom (Tooley & Darby, 1998). To address the limitations of both qualitative and quantitative methods, a number of researchers have used a mixed-methods approach, tailoring methods to different types of questions within the research design (Bennett et al., 1997). The present study primarily used qualitative methods supplemented by data from teacher-completed rating scales and standardized assessments.

### Participants

The parents of 66 out of the 69 children agreed to be interviewed and served as the participants for this study. The parents had 21 children attending special schools (10 residential, 11 local) and 45 in mainstream. All children in special schools were actively involved in speech and language therapy, as were five of the six children in mainstream schools with designated special provision and 70% of those integrated individually into mainstream schools. The nature of this varied, with intensity being greatest in special schools that had speech and language therapists on staff to work with teachers and provide direct therapy. Children in mainstream schools received therapy from visiting therapists, typically no more than once a week and often much less frequently. The majority of interviews were carried out with mothers only (73%). In 21% of the interviews, both parents were present. The four remaining interviews occurred with the father alone ( $n = 2$ ) or with the mother and grandmother ( $n = 2$ ).

### Measures

This article focuses on parental perspectives as noted in interviews but also draws on the results of the standardized questionnaire completed by the parents, the *Strengths and Difficulties Questionnaire* (SDQ), a revision and extension of the Rutter parent and teacher questionnaires (Goodman, 1994, 1997). The SDQ is composed of five scales: Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Problems, and Prosocial. Each scale comprises five items that are marked "not true," "somewhat true," or "certainly true," resulting in scores of 0, 1, or 2. Each of the five scales can result in a score from 0 (where no item is true) to 10 (where all items are true). The scores of the first four scales can be summed to produce a Total Difficulties score (range 0–40); the Prosocial scale provides a separate score for positive behavior. Goodman (1997) presented evidence for the concurrent and predictive validity of the SDQ as well as standardization data for the cutoff points for each scale and the Total Difficulties score to indicate children as likely psychiatric cases with 80% "normal," 10% "borderline," and 10% "abnormal" in each case. Further information on the relationship between parent- and teacher-completed SDQ, together with measures of self-esteem, language, and attainment are presented in Lindsay and Dockrell (2000).

### Procedure

The parents were sent the SDQ by mail, and about 2 weeks later two junior researchers visited them at home to conduct the interview. The completed questionnaires were collected after the interview had concluded.

The parents' views of their children's development were obtained by open-ended semistructured interviews. A schedule of major topic areas was devised by the researchers from a review of the literature and pilot interviews with parents of children with SSID who were not part of the current cohort. The development was aided by the project's steering group, which included a representative of the main voluntary body for parents of children with language difficulties in the United Kingdom (i.e., Afasic). Main topic questions were supplemented by probes, which were used if information was not produced spontaneously.

The parent interview focused on the following areas: identification and assessment of the child, including primary and secondary needs; the child in relationship to peers and siblings; the child's strengths and difficulties across the curriculum; the child's school life and home life, including social relations; the child's self-esteem; what the child likes to do; extra support provided in school; professionals involved with the child; parents' relationship with the child's schools and professionals; parents' thoughts about the child's future and the optimal provision for him or her; and parents' thoughts regarding their experiences.

To begin the interview, the researcher explained that the project was considering children with a wide range of difficulties, from those with a few minor problems to those with many severe problems. The interviewer then explained that because parents know most about their children, we would be speaking to them as the first step in the project. They were asked for permission to tape the interview and were assured that all information was confidential and that neither they nor their child would be personally identified.

Interviews were undertaken in the parents' homes and typically lasted about 1 to 1½ hours. The interviewer took the lead from the parent, allowing him or her time to talk about personal experiences and salient issues related to each area. These issues provided a structure for organizing the results.

Interviews were transcribed by the researcher who carried out the interview. The authors read the interviews to develop an initial coding frame based on the interview questions. The junior researchers, who had degrees in psychology, coded the interviews using the ATLAS/ti program for computer-based qualitative interview analysis (Muhr, 1997). The authors and junior researchers and a third, independent researcher with a degree in child development read all the interviews to develop a revised set of codes with five main issues and sub-categories:

1. the child's special educational needs;
2. the initial identification of the child's problem;



3. the type and quality of the support the child was receiving;
4. the wider impact of the child's difficulties on the family; and
5. parents' hopes, plans, and concerns for their child's future.

There were subcategories for each issue. For example, "views on their child's special educational needs" was composed of the following subcategories: difficulties with language, literacy problems, behavioral difficulties, social relationships (when a positive peer relationship subcategory was also included), attention and hyperactivity, and disruptive behavior. The junior researchers coded all interviews for the issues and subcategories; both authors read 10% of the interviews, and interrater agreement on subcategories was 92%. The subcategories were used in reporting the results.

## Results

In this section, we report the emergent issues and indications of their frequency and compare the perspectives of parents whose children are in mainstream and special schools. When appropriate, results from the SDQ are also reported using chi-square to compare the distribution of scores (normal, borderline, abnormal) with the 80:10:10 ratio expected from the standardization (see Table 1).

### *Parents' Views of Their Children's Special Educational Needs*

Parents were aware of their children's language difficulties and a range of other needs that their children experienced. Eighty-five percent recognized their child's primary problem was with language, but a minority considered this problem secondary to other difficulties. More than half the parents also highlighted literacy problems that were confirmed by conventional reading measures (Dockrell & Lindsay, 1998, 2002). Behavioral difficulties were reported by more than one third of parents, which is in keeping with the 37% who rated their child "abnormal" on the Total Difficulties score of the SDQ. This difference from the expected distribution was statistically highly significant,  $\chi^2(2, N = 60) = 61.85, p < .001$ , Effect Size Index  $w = 1.02$ , representing a large effect (Cohen, 1988). The difficulties identified at interview comprised several subcategories, indicating the complex nature of the impact of communication difficulties on this domain.

There were variations in the parents' perceptions of the children's social relationships, as evidenced by the interview and SDQ data. More than a quarter (27%) identified problems during the interview (e.g., "I just wish she could make friends—she's on her own all the time"). A higher proportion (46%) rated peer problems as abnormal on the SDQ (see Table 1). However, during the interview, parents reported many of the

**TABLE 1.** Parents' Ratings of Their Children on the SDQ

Scale	Normal (%)	Borderline (%)	Abnormal (%)
Emotional Symptoms	63.1	4.6	32.3
Conduct Problems	47.0	16.7	36.4
Hyperactivity	43.1	12.3	44.6
Peer Problems	40.0	13.8	46.2
Prosocial	84.4	4.7	10.9
Total Difficulties	41.7	21.6	36.7

Note. SDQ = *Strengths and Difficulties Questionnaire* (Goodman, 1994).  $N = 66$ .

children to be positively involved in friendship groups at both home (41%) and school (59%). Of particular interest with respect to inclusion is the finding that similar proportions of parents of children in mainstream and special schools (more than 80% in each case) reported that there were no negative aspects concerning friendship groups in school.

The SDQ tended to highlight problems by the specific nature of the questions asked. For example, the issue of bullying was not raised specifically during the interview, but 22% of parents reported on the SDQ that it was "certainly true" that their child was bullied and 27% that this was "somewhat true"; we found no difference between reports of parents of children in mainstream classrooms and special schools. At interview, however, parents discussed their child holistically, making positive comments as well as expressing concern. Strengths were also reported in prosocial behavior, as indicated above; indeed, this was the only scale on the SDQ for which there was no statistically significant difference when compared with the standardization sample,  $\chi^2(2, N = 64) = 2.02, p = .37$ .

Other concerns that were frequently reported during the interviews were related to attention and hyperactivity (26%) and disruptive behavior (23%), as evidenced in the following comments: "He is very hard to make sit still" and "His concentration is poor." Concerns about concentration and attention were revealed more frequently by the SDQ, on which 45% of parents rated their children as "abnormal" on the Hyperactivity scale, a finding that is statistically significantly above the expected rate when compared with the standardization sample,  $\chi^2(2, N = 65) = 89.31, p < .001, w = 1.17$ . Parents also noted concerns about disruptive behavior, with 37% rating conduct problems as abnormal on the SDQ,  $\chi^2(2, N = 66) = 57.81, p < .001, w = 0.94$ . In each case, the effect size is large. The latter domain was typically presented as either a result of the child's communication difficulties (e.g., "He used to get angry because he couldn't get his words across") or as a comorbid characteristic (e.g., "He's got a temper, and if he can't express himself sometimes it shows itself that way").

The children in mainstream classrooms ( $M = 6.45$ ,  $SD = 2.62$ ) were rated on the SDQ as having more problems with hyperactivity than children in special provision ( $M = 4.82$ ,  $SD = 2.17$ ), a statistically significant finding,  $t(65) = 2.57$ ,  $p = .013$  (two-tailed),  $d = .70$ . The mainstreamed children ( $M = 3.23$ ,  $SD = 2.33$ ) were also rated on the SDQ as having more conduct problems than children in special provision ( $M = 2.09$ ,  $SD = 1.60$ ),  $t(66) = 2.05$ ,  $p = .044$  (two-tailed),  $d = .58$ . Finally, the children in mainstream classrooms ( $M = 17.00$ ,  $SD = 7.57$ ) received higher Total Difficulties scores on the SDQ than did children receiving special provision ( $M = 12.76$ ,  $SD = 4.89$ ),  $t(60) = 2.63$ ,  $p = .011$  (two-tailed),  $d = .68$ .

Parents' responses to both the interviews and the SDQ indicate that these children with SSLD have a range of comorbid difficulties, including high levels of hyperactivity, poor concentration, and impaired peer relationships, in addition to the expected language and educational problems. The greater prevalence of these problems in mainstreamed children raises important questions about inclusion, including whether these behavioral difficulties were a result of a failure to meet these children's language and educational needs. The use of both methods has furthermore produced not only cross-validation but also useful complementary information: The SDQ focused parents on specific characteristics and difficulties, whereas the interview helped us attain a more holistic representation of the child, including his or her positive features.

### *Initial Identification of the Problem*

The second issue concerns identifying developmental difficulties during early childhood. Parents reported that they played a key role in identification and that this had often been a frus-

trating process. Almost half (47%) reported that they were the first to notice a problem. Parents were acting on their own suspicions that something was wrong, which were often influenced by knowledge from family history. A quarter reported either a parent or a sibling having some form of speech or language difficulty: "It runs in the family, so we picked it up" (mother); "I went to a speech therapist when I was a young chap for stuttering when I was about 5" (father).

Professionals were often seen as dismissive—parents reported being told to come back later. This sometimes happened more than once, resulting in a very lengthy process that in some cases was delayed until the child attended nursery school (kindergarten): "My only grievance is that things didn't happen sooner"; "We went to the child development unit. They said he was just fine." There was also concern that the nursery had not noticed anything wrong: "I think nursery should have picked up on it."

These findings indicate the importance of parents in early identification but also highlight the need for partnership. Parental expertise may be enhanced by previous experience with an older child. Optimal identification processes require the joint involvement of parents and professionals, with professionals prepared to address parental concerns positively.

### *Meeting the Child's Needs*

The parents identified concerns about meeting their child's needs, which were classified into seven categories. There were statistically significant differences between parents of children in mainstream classrooms ( $n = 21$ ) and special schools ( $n = 45$ ) in three of these categories, all of which had implications for inclusion (see Figure 1).

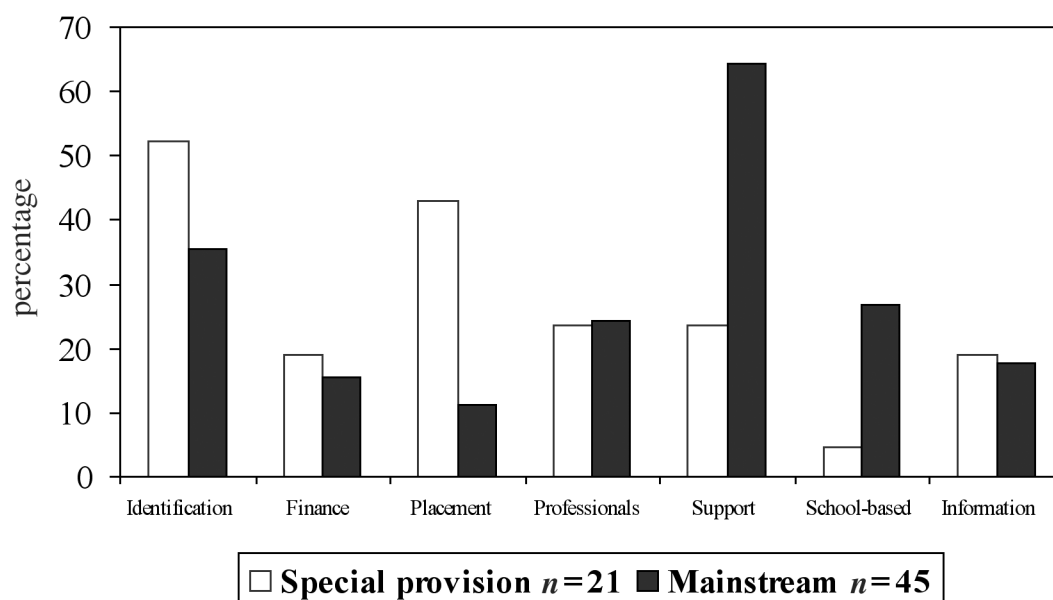


FIGURE 1. Percentage of parents with children in mainstream and special schools who identified problems in meeting their child's educational needs.

Problems with placement were raised significantly more often by parents in special schools,  $\chi^2(1, N = 66) = 8.63, p = .003$ , Cramer's  $V = 0.33$ , which accounts for 11% of the variance. These parents reported having to fight hard to secure special school placement for their child. Such battles could be prolonged and upsetting, as shown by the following statements: "It was me who campaigned his corner, who fought, who wrote letters" and "I think there has to be a shake up down there, because to go through the trauma you've got to go through for 18 months to get somebody to a school . . . it was very distressing."

However, securing the appropriate levels of support within the school was a more frequent problem for mainstream parents,  $\chi^2(1, N = 66) = 9.47, p = .002$ , Cramer's  $V = 0.38$ , which accounts for 14% of the variance. Examples of concerns follow: "The plans are sound, but they just never seem to get done"; "The school would like to do more but have not the time nor the resources"; and "They said that he needs specialized schooling really, and they can't offer it to him, and I can't offer it because I am not a teacher."

By corollary, parents of children in mainstream provision were also more likely to express concern about school-based problems, including class size and school organization,  $\chi^2(1, N = 66) = 4.34, p = .037$ , Cramer's  $V = 0.26$ , which accounts for 7% of the variance.

Both groups were equally concerned about earlier problems with identification, with 41% of all parents reporting such difficulties. Parents also reported problems with financing of appropriate provision (17%) and the time available for discussion and dissemination of information (18% overall): "Unless we approach, we don't know anything." Both groups also expressed concern over frequent changes in SLTs, resulting in a lack of amount and consistency of speech and language therapy. In addition, parents of children in mainstream classrooms felt that their child did not get enough expert help from SLTs, who were reported to visit infrequently and leave work for the teacher or teaching assistant to do with the child rather than undertake direct therapy.

These findings indicate that parents of children in mainstream classrooms and parents of children in special schools had different experiences and battles. Parents of children in special schools fought to gain special services against a system that was mainly based on inclusion. Parents of children in mainstream classrooms supported inclusion but were unhappy with the services actually provided for their children. If parents are to be satisfied with a move to even greater levels of inclusion, more attention must be paid to the level of service provided.

### *Impact on the Family*

The children's special needs affected families in a range of different ways, which were in some respects independent of the nature of the schooling. Communication difficulties were one source of stress for parents: "I used to get really depressed. I

used to find it really hard trying to communicate with him. . . . I couldn't understand why we were like we were."

The impact on siblings was also mentioned. Some parents said there had been problems resulting from communication difficulties: "He used to get very frustrated. . . . If he couldn't find the right words to ask her [his sister] to move, he'd just get hold of her hair and drag her across the room." Parents also discussed this issue in terms of fairness, as exemplified by one mother's comments about her typically developing child's successes: "I didn't want her to do it [succeed in a swimming assessment]. I was dreading it in a way. It sounds awful because obviously I want her to do well, but I just didn't want his confidence to be knocked either." Problems also arose as a result of residential schooling: "I think it will be harder on his brothers. Their brother is being sent away, and they are going to miss him." However, siblings were also a source of extra support: "She's quite capable of telling them why she's screaming or why she's doing that. She's very good with her."

Other impacts were related to the child's schooling. Forty-seven percent of the parents reported being actively involved in supporting their child's language and learning needs, the nature of which was partly determined by the proximity of the school. If the child attended a local school, parents often visited and worked in the school: "I used to go in and teach him every day." Others worked with the child at home:

She gave us things to do every night, trying to make him pronounce sounds that he had difficulty with. . . . We would have to get him to learn words. We would do things like cut them out and put them on a bit of paper and we would play cards with him. . . . I would say to him, "What is that?" and sometimes he remembered and other times he didn't, but that was all things we had to do.

This extra involvement sometimes had repercussions on the child and family: "The trouble is, you end up doing so many things after school and you think, 'poor child.'" Parent support within the school could also have drawbacks:

Because we have to help him, because he's got learning difficulties, because we go up to the school every day to help him at school, the other children say, "Why are your mum and dad here to help you? They shouldn't be here." And that gets to him.

The need for guidance was also apparent: "We go through his folder with him . . . but I really don't know how to do it properly."

Having a child with SS LD had an impact on the family as a whole. This could include difficulties within the family (e.g., with siblings), but the active involvement of almost half the parents in the children's education provides another source

of stress as well as a potential for positive, collaborative action with professionals. However, such practice needs to be based on knowledge and expertise if it is to be effective. Parents often have the knowledge, but not necessarily the skills, to address some of their children's problems. Unless professionals support them, parents can be exposed, unsuccessful, and frustrated as they struggle to devise effective educational interventions.

### *The Future*

Parents also expressed their hopes and plans and, especially, their concerns for the future. Once more, these comments were relevant to inclusion. For example, 8 out of 10 parents whose children were attending residential special provision saw the child's educational future in special schooling and were preparing for future battles:

We know that after this September we will have to start fighting in order to secure his place [for secondary school]. I have already written to my barrister in London saying that we will be starting this fight and if we need his services . . . that is the only way we are going to do it.

The other two hoped their child would return to a mainstream classroom but commented that this was not a "realistic option": "Ideally, it would be great if it all came together and she could integrate into a normal school and be near home. Realistically, I see her being here until she is 16." Parents of children in mainstream classrooms, however, overwhelmingly wanted this to continue. Indeed, only one parent with a child who was mainstreamed referred to a perceived benefit of special schools: "If he went to special school, nobody could say anything about him being different."

The main concerns for the parents of children in mainstream classrooms focused on two issues. First, parents referred to their hopes for their child overcoming his or her difficulties, whether with social skills, communication ("Well, I hope her speech gets all right, you know. I suppose it will eventually"), or literacy ("If she could just learn to read and write"). A number of parents of children in mainstream were concerned that as their child became older he or she would be ridiculed and become more aware of his or her difficulties and that this would "get them down." This could be aggravated by the extra support provided:

I hope that . . . he won't need it [extra help] because I think it is more difficult for them when they are in big school if they are getting help from the other kids. More so than at his age because I don't think they realize when [one student] goes off for help, but when he goes to the big school, I think they do. So I am hoping that he will be all right by the time he gets to big school.

Second, parents hoped that their child could continue to attend mainstream school and that levels of support would continue:

I know he probably won't ever be able to catch up to their level, but you know at least if he can keep going and the school keeps having faith in him and don't hold him back again. That's the only thing I'm worried about—that after so long, they are going to say there is no more we can do for him, he has got to go back to a special needs school.

The strong commitment to the current system by parents of children in both mainstream and special schools poses a dilemma for policymakers. A move toward greater inclusion will be troublesome for parents whose children attend special schools and must be supported by appropriate resources to meet the aspirations of parents who support inclusion.

## Discussion

This study described the perspectives of parents of children with SSLD who attended both mainstream and special schools, including those that are residential. These views were considered with respect to the role of parents in the education of children with disabilities and, in particular, as this relates to inclusive education.

The study was conducted on a relatively small scale, with a sample size of 66 parents, and was limited to parents of children with SSLD. However, the sample was drawn from two different areas, one largely urban and the other a mixture of urban and rural settings, and represents a random selection of children with SSLD in those areas. Also, the confidence that can be placed in the results is boosted by the effect sizes for the analyses of SDQ data and by the consistency between the quantitative and qualitative evidence.

Legislation in the United Kingdom, the United States, and other countries demands that parental views be taken into account. This issue concerns parents' rights to be involved in decisions about their children. However, the importance of parental perspectives goes beyond rights to the efficacy of the system's operation. These parents were key figures in the initial identification of their child's problems and had a sound understanding of their children's strengths and needs, as evidenced by the concordance between the parents' perspectives and the standardized measures. The high level of reported incidence of SSLD by family members highlights children's increased risk as well as parents' sensitivity to identification (Bishop et al., 1999). However, the parents in this study thought they were often not listened to, both at the outset and later, and that they had to fight hard for appropriate support services or entry to an appropriate school for their children. Difficulties in identifying appropriate services are likely to reduce the early identification of favorable environmental niches to support development. Thus, despite these parents' real con-



cerns about the needs of their children, early appropriate provision was often not forthcoming.

Perspectives of parents whose children attend mainstream or special schools indicate the complexity of the inclusion issue. This is often presented as a question of rights, but as Lindsay (1997) argued, that is insufficient. Both the surmounting of barriers and the efficacy of the education provided must also be considered (Buysse, Wesley, & Keyes, 1998; Manset & Semmel, 1997; Mills, Cole, Jenkins, & Dale, 1998). Inclusion may be in tension with another important value, the promotion of informed choice. Many parents in this sample felt ill-informed about the ways in which their children's needs were being met at school. There was a clear division with respect to inclusion between parents of children in mainstream classrooms and those of children in special schools, with each favoring the type of education setting currently provided for their child.

The movement toward a system of total inclusive schooling would remove the right of choice from parents who seek special education for their children. A further dimension, however, is efficacy of the education provided. The majority of parents whose children are mainstreamed wanted their children to continue in mainstream classrooms, but many were concerned that the support provided was inadequate. Parents of children in special schools had often battled to secure their child's place in the school but were now content with the amount and nature of support made. Hence, parents will be faced with the dilemma of deciding between the inclusive ideal offered by mainstream education and the better resources and potential to optimize educational progress offered by special schools.

For parents of children with speech and language needs, the provision of speech and language therapy is also a factor. Parents of mainstreamed children were concerned about both the amount and the type of delivery of these services. In special schools, SLTs worked on site and could collaborate on programs. In mainstream schools, however, a consultation model of practice had been developed in which SLTs advised teachers. Many parents were suspicious of this lack of direct therapy, a method that is appropriate for 8-year-old children with severe speech and language difficulties; this concern was also reported in a national study of speech and language needs in the United Kingdom (Law et al., 2002). At present, too little is known about teachers' implementation of interventions following consultation (Noell & Witt, 1999). Parents also had concerns for the future. In general, those whose children were in special provision viewed continuation as a realistic option, whereas those whose children were mainstreamed had serious doubts about the support available at secondary school (usually attended from age 11 years). This diversity of opinion indicates the complexity of parental views on inclusion and, in particular, the different bases of opinions. Some parents emphasize value positions concerning normality, whereas others give higher priority to improving language and educational abilities (Palmer et al., 1998).

The present study extends the evidence previously available on younger children and those with either severe developmental delays or learning disabilities, reporting the perspectives of parents of children with SSLD who were about 8 years old, in their 4th year of compulsory schooling in the English school system. The children's difficulties were not obvious at birth nor in the early months, unlike children with severe and profound sensory, physical, and intellectual developmental impairments. Their problems are not limited to speech and language, however. This group is at risk of experiencing significant educational, social, and behavioral difficulties (Bishop, 2001; Lindsay & Dockrell, 2000; Lindsay, Dockrell, Letchford, & Mackie, 2002; Tomblin, Zhang, Buckwalter, & Catts, 2000). They require programs that address both educational and speech and language goals.

Regarding parents as partners has been an increasingly important cornerstone of British government policy (e.g., Department for Education and Skills, 2001) and professional practice. However, there are several models of partnership. The current study questions the rhetoric of parent partnership from identification to provision. Parents were certainly involved in identification, but decisions on the nature and extent of the provision generally remained in the domain of professionals, unless parents were prepared to fight for what they felt was appropriate; interestingly, these tended to be parents seeking a special school placement. Parents were also concerned about the time taken to assess and decide on provision. Under these circumstances, the concept of partnership, despite the intentions of professionals and managers, becomes strained. This is partly a matter of communication and partly a result of real conflicts in the system, including financial priorities. True partnership requires more creative and effective approaches (Buysse, Wesley, & Skinner, 1999; Law et al., 2000).

Parents have an important role in mediating the development of children with developmental difficulties. Bronfenbrenner's ecological systems theory provides a useful approach to conceptualizing their involvement, and the present study provides evidence at each of the four levels. At the microsystem level, parents contribute directly to intervention programs, both at home and at school. They also experience and can report on the interaction of the child's difficulties with the family. Parents are also involved in the mesosystem, as evidenced by their concerns about the implementation of inclusion by schools and SLTs, including the latter's consultation model. When professionals decide to change working practice because they consider the new method to be more effective and/or efficient, they need to gain the support and understanding of key stakeholders, in this case the parents. At the level of the exosystem, parental perspectives provide important information to guide local strategic policy formation and implementation for the education and health systems. Finally, at the macrosystem level, parents' perspectives on the working of support systems, including inclusion, provide relevant and important information that influences value systems and national laws. The determination of some parents to continue

to have their child's needs met in specialist provision is an important message for policymakers.

### AUTHORS' NOTES

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### REFERENCES

- Anzul, M., Evans, J. F., King, R., & Tellier-Robinson, D. (2001). Moving beyond a deficit perspective with qualitative research methods. *Exceptional Children, 67*, 235–249.
- Bailey, D. B., Skinner, D., Rodriguez, P., Gut, D., & Correa, V. (1999). Awareness, use and satisfaction with services for Latino parents of children with disabilities. *Exceptional Children, 65*, 367–381.
- Bailey, D. B., & Winton, P. J. (1987). Stability and change in parents' expectations about mainstreaming. *Topics in Early Childhood Special Education, 7*, 73–88.
- Bennett, T., DeLuca, D., & Bruns, D. (1997). Putting inclusion into practice: Perspectives of teachers and parents. *Exceptional Children, 64*, 115–131.
- Bennett, T., Niswander, V., & DeLuca, D. A. (1996). Visions of inclusion. *The School Community Journal, 6*, 15–28.
- Bishop, D. V. M. (1997). *Uncommon understanding: Development and disorders of language comprehension in children*. Hove, England: Psychology Press.
- Bishop, D. (2001). Genetic influences on language impairment and literacy problems in children: Same or different? *Journal of Child Psychology and Psychiatry, 42*, 189–198.
- Bishop, D. V. M., Bishop, S. S., Bright, P., James, C., Delaney, T., & Tallal, P. (1999). Different origin of auditory and phonological processing problems in children with language impairment: Evidence from a twin study. *Journal of Speech, Language and Hearing Research, 42*, 155–168.
- Botting, N., & Conti-Ramsden, G. (2000). Social and behavioral difficulties in children with language impairment. *Child Language Teaching and Therapy, 16*, 105–120.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Bronfenbrenner, U. (1992). Ecological systems theory. In R. Vasta (Ed.), *Annals of child development. Six theories of child development: Revised formulations and current issues* (pp. 187–249). London: Jessica Kingsley.
- Buysse, V., Wesley, P. W., & Keyes, L. (1998). Implementing early childhood inclusion: Barrier and support factors. *Early Childhood Research Quarterly, 13*, 169–184.
- Buysse, V., Wesley, P. W., & Skinner, D. (1999). Community development approaches for early intervention. *Topics in Early Childhood Special Education, 19*, 236–243.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (Rev. ed.). Hillsdale, NJ: Erlbaum.
- Denzin, N., & Lincoln, Y. S. (Eds.). (2000). *Handbook of qualitative research* (Rev. ed.). Thousand Oaks, CA: Sage.
- Department for Education. (1996). *Education Act 1996*. London: Author.
- Department for Education and Employment. (1997). *Excellence for all children: Meeting special educational needs*. London: Author.
- Department for Education and Employment. (1998). *Meeting special educational needs: A programme for action*. Sudbury, England: Author.
- Department for Education and Skills. (2001). *Special educational needs code of practice*. Nottingham, England: Author.
- Diamond, K. E., & LeFurgy, W. G. (1994). Attitudes of parents of preschool children toward integration. *Early Education and Development, 5*(1), 69–77.
- Dockrell J. E., George, R., Lindsay, G., & Roux, J. (1997). Professionals' understanding of specific language impairments: Implications for assessment and identification. *Educational Psychology in Practice, 13*, 27–35.
- Dockrell, J. E., & Lindsay, G. (1998). The ways in which children's speech and language difficulties impact on access to the curriculum. *Child Language Teaching and Therapy, 14*, 117–133.
- Dockrell, J. E., & Lindsay, G. (2001). Children with specific speech and language difficulties—The teachers' perspective. *Oxford Review of Education, 27*, 369–394.
- Dockrell, J. E., & Lindsay, G. (2002). The impact of specific language difficulties on learning and literacy. In Centre for Educational Research (Ed.), *Learning and teaching: Contemporary research approaches* (pp. 187–203). Athens, Greece: Centre for Educational Research.
- Duhaney, L. M. G., & Salend, S. J. (2000). Parental perceptions of inclusive special education placements. *Remedial and Special Education, 21*, 121–128.
- Erwin, E. J., & Soodak, L. C. (1995). I never knew I could stand up to the system: Families' perspectives on pursuing inclusive education. *Journal of the Association for Persons with Severe Handicaps, 20*, 136–146.
- Galant, K., & Hanline, M. F. (1993). Parental attitudes toward mainstreaming young children with disabilities. *Childhood Education, 69*, 293–297.
- Goodman, R. (1994). A modified version of the Rutter parent questionnaire including extra items on children's strengths: A research note. *Journal of Child Psychology and Psychiatry, 35*, 1483–1494.
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry, 38*, 581–586.
- Granlund, M., & Rolfs-Pettersson, L. (2001). The perceived needs of support of parents and classroom teachers—A comparison of needs in two micro-systems. *European Journal of Special Needs Education, 16*, 225–244.
- Grider, J. R. (1995). Full inclusion: A practitioner's perspective. *Focus on Autistic Behavior, 10*, 1–11.
- Grove, K. A., & Fisher, D. (1999). Entrepreneurs of meaning: Parents and the process of inclusive education. *Remedial and Special Education, 20*, 208–215.
- Guralnick, M. J. (1994). Mothers' perceptions of the benefits and drawbacks of early childhood mainstreaming. *Journal of Early Intervention, 18*, 168–183.
- Guralnick, M. J., Connor, R. T., & Hammond, M. (1995). Parent perspectives of peer relationships and friendships in integrated and specialized programs. *American Journal of Mental Retardation, 99*, 457–476.
- Hewson, J., & Sisson, S. (1996). Parents prefer inclusion: The views of parents of children with special educational needs in one mainstream nursery school. *Early Years, 17*, 26–31.
- Huefner, D. S. (2000). The risks and opportunities of the IEP requirements under IDEA '97. *The Journal of Special Education, 33*, 195–204.
- Individuals with Disabilities Education Act Amendments of 1997, 20 U.S.C. §1401 (26)
- Law, J., Lindsay, G., Peacey, N., Gascoigne, M., Soloff, N., Radford, J., et al. (2000). *Provision for children with speech and language difficulties: Facilitating communication between education and health services*. Nottingham, England: Department for Education and Employment and Department of Health.
- Law, J., Lindsay, G., Peacey, N., Gascoigne, M., Soloff, N., Radford, J., et al. (2002). Consultation as a model for providing speech and language therapy in schools: A panacea or one step too far? *Child Language Teaching and Therapy, 18*, 145–163.
- Leonard, L. (1998). *Children with specific language impairment*. Cambridge, MA: MIT Press.
- Lewis, A., & Lindsay, G. (Eds.). (2001). *Researching children's perspectives*. Milton Keynes, England: Open University Press.
- Lindsay, G. (1995). Early identification of special educational needs. In I. Lunt, B. Norwich, & V. Varma (Eds.), *Psychology and education for special needs: Recent developments and future directions* (pp. 7–24). London: Arena, Ashgate Publishing.
- Lindsay, G. (1997). Are we ready for inclusion? In G. Lindsay & D. Thompson (Eds.), *Values into practice in special education* (pp. 89–103). London: David Fulton.

- Lindsay, G., & Dockrell, J. E. (2000). The behavior and self-esteem of children with specific speech and language difficulties. *British Journal of Educational Psychology*, 70, 583–601.
- Lindsay, G., Dockrell, J. E., Letchford, R., & Mackie, C. (2002). Self esteem of children with specific speech and language difficulties. *Child Language Teaching and Therapy*, 18, 125–143.
- Lindsay, G., Dockrell, J., Mackie, C., & Letchford, B. (2002). *Educational provision for children with specific speech and language difficulties*. Coventry, England: University of Warwick, Center for Educational Development, Appraisal and Research.
- Manset, G., & Semmel, M. I. (1997). Are inclusive programs for students with mild disabilities effective? A comparative review of model programs. *The Journal of Special Education*, 31, 155–160.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis* (Rev. ed.). London: Sage.
- Miller, L. J., Strain, P. S., Boyd, K., Hunsicker, S., McKinley, J., & Wu, A. (1992). Parental attitudes toward integration. *Topics in Early Childhood Special Education*, 12, 230–246.
- Mills, P. E., Cole, K. N., Jenkins, J. R., & Dale, P. S. (1998). Effects of differing levels of inclusion on preschoolers with disabilities. *Exceptional Children*, 65, 79–90.
- Muhr, T. (1997). ATLAS.ti. Visual qualitative data analysis management model building (Version 4.1) [Computer software]. Berlin: Scientific Software Development.
- Noell, G. H., & Witt, J. C. (1999). When does consultation lead to intervention implementation? *The Journal of Special Education*, 33, 29–35.
- Palmer, D. S., Borthwick-Duffy, S. A., & Widaman, K. (1998). Parent perceptions of inclusive practices for their children with significant cognitive disabilities. *Exceptional Children*, 64, 271–282.
- Palmer, D. S., Fuller, K., Arora, T., & Nelson, M. (2001). Taking sides: Parent views on inclusion for their children with severe disabilities. *Exceptional Children*, 67, 467–484.
- Petley, K. (1994). An investigation into the experiences of parents and head teachers involved in the integration of primary aged children with Down's syndrome into mainstream school. *Down's Syndrome: Research and Practice*, 2, 91–96.
- Pugach, M. C. (2001). The stories we choose to tell: Fulfilling the promise of qualitative research for special education. *Exceptional Children*, 67, 439–453.
- Riddell, S., Brown, S., & Duffield, J. (1994). Parental power and special educational needs: The case of specific learning difficulties. *British Educational Research Journal*, 20, 327–344.
- Roffey, S. (1999). *Special needs in the early years: Collaboration, communication and co-ordination*. London: David Fulton.
- Ryndak, D. L., Downing, J. E., Lilly, R. J., & Morrison, A. P. (1995). Parents' perceptions after inclusion of their children with moderate or severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 20, 147–157.
- Schwartz, I. S., Staub, D., Galluci, C., & Peck, C. A. (1995). Blending qualitative and behavior analytic research methods to evaluate outcomes in inclusive schools. *Journal of Behavioral Education*, 5, 93–106.
- Seery, M. E., Davis, P. M., & Johnson, L. J. (2000). Seeing eye-to-eye: Are parents and professionals in agreement about the benefits of preschool inclusion? *Remedial and Special Education*, 21, 268–278.
- Special Educational Needs Tribunal. (2000). *Special educational needs tribunal: Annual report 1999–2000*. Sudbury, England: Department for Education and Employment.
- Stokes, J. (1993). Parental perspective: The mainstream education of a child with a severe visual impairment. *The British Journal of Visual Impairment*, 11, 97–98.
- Tomblin, J. B., Zhang, X., Buckwalter, P., & Catts, H. (2000). The association of reading disability, behavioral disorders, and language impairment among second-grade children. *Journal of Child Psychology and Psychiatry*, 41, 473–482.
- Tooley, J., & Darby, D. (1998). *Educational research: A critique*. London: Office for Standards in Education.
- Wesley, P. W., Buysse, V., & Tyndall, S. (1997). Family and professional perspectives on early intervention: An exploration using focus groups. *Topics in Early Childhood Special Education*, 17, 435–456.
- Wolfendale, S., & Bastiani, J. (2000). *The contribution of parents to school effectiveness*. London: David Fulton.
- York, J., & Tundidor, M. (1995). Issues raised in the name of inclusion: Perspectives of educators, parents and students. *Journal of the Association for Persons with Severe Handicaps*, 20, 31–44.